



Living with a diagnosis of non-small cell lung cancer: patients' lived experiences

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Abstract

The aim of this study was to explore patients' experience of living with non-small cell lung cancer (NSCLC). Patients diagnosed with NSCLC know that their treatment is not with curative intent and can expect distressing symptoms. In this phenomenological study, six adults with a diagnosis of NSCLC were interviewed. Data was analysed guided by van Manen's six-step process. Four main themes were interpreted: 'Maintaining my life'; 'The enemy within'; 'Staying on the train', and 'I'm still me'. The study findings contribute to nurses' understanding of patients living with this distressing diagnosis where treatment is palliative. Understanding these patients' experience can help nurses to interact in a different way, and to maximise opportunities to care holistically for this group of patients and best meet their needs.

Key words: Non-small cell lung cancer (NSCLC), phenomenology, palliative.

Introduction

This study explored patients' experience of living with a diagnosis of non-small cell lung cancer (NSCLC). Despite the improvements in treatment options, advanced NSCLC remains a palliative diagnosis, with a poor long-term prognosis.

This cancer and its treatment, results in difficult symptoms for patients. Considerable empirical studies have been reported on the physical and emotional distress caused by a lung cancer (e.g. Zabora et al, 2001; Cooley et al, 2003; Li and Grigis, 2006; Akechi et al, 2006). However, there is a dearth of literature reporting qualitative findings on this topic. Berterö et al, (2008) reports on the lived experience of lung cancer patients in Sweden. In addition, Yardley et al, (2001) reports on patients' experiences of receiving a diagnosis of lung cancer, rather than their experiences of being treated for and living with a diagnosis of NSCLC.

NSCLC is the most common type of lung cancer, comprising approximately 80% of all cases (Tyson 2007). At presentation, more than two thirds of patients will have advanced disease, as lung cancer may be present for many years before symptoms appear (Tyson, 2007; Molina et al, 2008).

The mainstay of treatment for advanced NSCLC remains systemic chemotherapy (Fathi and Brahmer, 2008; Waxman, 2008). However, the median survival of a patient newly diagnosed with advanced NSCLC is 8-10 months with an overall survival rate of 30-35% when treated with standard chemotherapy (Sequist et al, 2007).

Between 40-80% of patients with NSCLC over express epidermal growth factor receptor (EGFR), and is associated with poorer prognosis (Molina et al, 2008). Cetuximab (Erbix), a monoclonal antibody, blocks growth stimulation by binding to the ligand-binding site of EGFR (Thatcher, 2007). In addition, Erlotinib (Tarceva), an EGFR-TK inhibitor, has achieved approval from the FDA for second and third line treatment of metastatic NSCLC. The introduction of these biological agents has offered more treatment options for lung cancer patients, and is changing the future of this disease (Grossi et al, 2008; Molina et al, 2008; Waxman, 2008).

Methodology

This study adopted an interpretive phenomenological approach guided by the writings of van Manen. According to van Manen (1997), when performing phenomenological research, the researcher undertakes a set of activities that focus on the phenomenon being investigated. These activities involve writing, reflecting and rewriting in pursuit of a description of the phenomenon. van Manen's approach to hermeneutic phenomenology was chosen because its focus is the lived experience. In addition, van Manen's description of the four lifeworld structures; time, space, time and lived relations, were considered appropriate for describing the participants' experiences of living with lung cancer.

The hospital's ethics committee granted ethical approval. Study participants (four women and two men) were purposefully chosen from a list of all patients receiving treatment for NSCLC at the hospital's oncology day unit. All participants invited to be interviewed had a diagnosis of metastatic non-small cell lung cancer, and were undergoing treatment (chemotherapy or maintenance treatment) at the time of being

interviewed. Patients who were considered medically unfit to be interviewed or were not fluent in English were excluded.

The study participants were invited to be interviewed by post. Verbal consent was obtained over the telephone prior to arranging the interview, and written consent was obtained before commencement of the interview. Participants' transcripts were given pseudonyms. The participants' ages ranged from 52 to 74 years of age.

Each participant was interviewed once. The interviews were open and lasted between 45-60 minutes. The participants chose the timing and location of the interviews, with all but one patient choosing their home as the interview setting. Holding the interviews in the participants' own environment is in keeping with the naturalistic approach, as it is where they experience life (Streubert and Carpenter, 1999). In addition, it may provide a sense of control to participants (McIlfatrick et al, 2006).

Reflexivity is an essential aspect of interpretive research, and this was pursued through the first author writing, reflecting and rewriting in a reflective journal. The process of analysis of the interview transcripts began with the reading and re-reading of the interview transcripts. This process is referred to as a 'holistic reading approach' (van Manen, 1997) and from this reading, the central meaning of the transcript as a whole was acquired. The transcripts were then read and re-read again to isolate the core views of the participants' lived experience. Following this, essential themes were interpreted. Reading of the transcripts was then selective to identify statements or phrases which represented the themes of the lived experience (Table 1).

Study findings

Theme 1: 'Maintaining my life'

Trying to maintain a normal life was one of the most important factors for the study participants. Participants also laughed as they recalled stories of climbing heights clipping hedges, and going to the pub all day playing darts, to the horror of family members, but seen as normal behaviour for the participant.

Mary: "...it takes me time after being in the hospital, to get back to what I call normal, and then when I come up to it again, for maybe 2 days before hand I'm thinking about it again, but its brilliant; having the two weeks gives me time to be normal again. And I think for me now personally, the more normal things are for me the better it is for me. I love having normality"

Marie: "I didn't let it in on me and I still don't think about it only when I get this pain in my back. I'd put on my dinner and cook and that sort of thing...I'm happy pottering around the house that's right"

Jim: "I get fed up at home then, I do be on my own a lot of the time and I'd go off walking now, go off walking, wind up past a pub somewhere, go in here, have a bit of craic, you always meet somebody have a bit of craic in here, that is one way of getting away from it"

All participants spoke of loss; loss of work, financial independence, loss of friendships and roles in the family. These losses affected negatively on their lives, and on their perception of themselves.

Mary: "...there is only so much you can do, but I find I miss work terribly. I miss the interaction with people..."

The impact of facing others with cancer varied for participants. Some participants spoke of sharing stories and ways of coping with the side effects of treatments and appreciated these interactions.

John: "There was one woman there, she was a stout block of a woman, she was with Dr. X as well and I don't see her either. She is missing as well; she had it in

the lungs too. She was getting chemo with me and I don't know what happened to her. ..I used to have a great chat with her"

Relationships were developed, with participants enquiring after patients they hadn't seen in a while, or expressing sadness for patients who had died.

Alice: *"You meet some lovely people..... it's nice to see the same faces, although you do wonder when you haven't seen someone in a while"*

Theme 2: 'The enemy within'

All of the study participants were concerned about changes in their body function and appearance. Participants described their bodies as barometers of how the cancer was going- each new pain or cough was viewed with suspicion, as indicating the cancer might be coming back.

Frances: *"I had a pain there in my ear and I was saying it to the doctor and he was very concerned about it. He was saying that some people that have cancer can end up with a pain in their ear. Do you think it could be spread?"*

All of the participants described fatigue as being particularly debilitating, and adversely affecting their day-to-day living.

Marie: *"Oh I would I could sit back here and I could sleep during the day time and go to bed for a couple of hours in the day and still sleep that night, sleep maybe until ten in the morning maybe half ten".*

Alice: *"I often am in bed by eight o'clock in the evening, I might try and read a book but I usually just fall asleep. I could sleep all night, and still find it hard to get up in the morning...."*

Frances: *"...the paper was there and I took up the paper to read it and the next thing you'd get kind of blur and you couldn't say if it was As or Bs or Cs and it would take you a half an hour to read a little short column. And then I had a book for one of the children and he was going to bed and I was reading it anyway and he was half asleep, he said 'here granny would you ever let me see that to see what story you are reading' and I'd be reading away and the next thing I'd go off and I'd say something that wasn't in it at all. And he would know well, he is only five. Little things like that."*

Hair loss was associated as the most visible sign of their cancer by all participants. Jim described his hair loss as the visible sign of his cancer, and when it grew back after completing his first cycle of chemo people then associated this as him being cured.

Jim: *“The only reason they knew [that he had cancer] was cause I lost the hair and that was the first time and then it all came back again. And you’d look and say there is nothing wrong with him, the hair had all grown back. After the 6 months then it had all come back again and here we go again.”*

However, for the female participants hair loss was a more complex issue. Mary found it intensely disturbing to have people looking at her and felt it as an invasion of her privacy that people knew she had cancer:

Mary: *“...we went to Portugal and it was the first time I felt if I went some where there was no one looking at me, they think of me then as a different person, ... that was the first time I just thought that this is just normal here I can be myself there...there is nobody looking at me saying oh look at her hair she’s wearing a hair piece, or she, or her hair is grey now or you know”.*

With the newer EGFR treatments, acne like skin rash is often experienced. This rash appears mostly on the face and upper torso.

Alice: *“Now I have this rash, and it’s a bit better now but, it used to be absolutely awful. And you can’t wear makeup over it, and you can’t even use the skin creams, you know the nice ones I used to use”*

John: *“The rash is something else, I’m on all these antibiotics for it but sure I don’t think they’re worth a curse. It got so bad he had to cut down one of the drugs”*

Theme 3: ‘Staying on the train’

The lack of choice was a recurrent theme amongst all participants; stopping treatment was not an option. Participants expressed the feeling of being caught in a cycle, of not having a choice, and of being unable to regain control of the situation.

Marie: *“I’d prefer to keep going with treatment than to be told that’s it now....Yeah, if they said that was the last of the treatment now, .. I wouldn’t feel good about it. That’s right, if you are getting treatment you are living in hope”*

John: *“But sure, if you don’t get the treatment you are not going to last anyway, simple as that....if you don’t keep it up you won’t stay going...”*

All the participants were aware that they were diagnosed with an incurable lung cancer, and that the only available conventional treatment option was chemotherapy.

Mary: *“...you are just so helpless, so helpless, you are waiting to see what next, what s going to happen next, I think the fact that you just can’t ever get away from it.”*

All the participants spoke about the length of time spent in the hospital, awaiting blood results, waiting to see the doctor and waiting for chemotherapy to arrive. All the staff were seen as being very busy, running around, with hardly time to talk. They all acknowledged their lack of choice in this, wanting to spend their time elsewhere but having no option but to wait patiently.

Mary: *“...even it’s getting busy and busier and the time seems to be getting longer and longer and you are spending more time in there...”*

Theme 4 ‘I’m still here’

Participants described putting on a brave face, not complaining in order to protect their loved ones.

Mary: *“I would tell them [family] that I’m fine, I’m fine but because they couldn’t see me; it is hard when you can’t see somebody I suppose, so yeah you would find that at times you would put on a brave face. So you know it is not easy.”*

Marie: *“Well that’s what I think, you have to get on with it and there is no use to sit down and complain to anyone nothing they can do nothing you can do”*

The importance of protecting the family and allowing them to have a normal life, or not allowing the participants’ cancer to take over their lives was evident:

Mary: *“I mean I want them to do everything they want to do I absolutely don't want them to feel they have to... *** [daughter] comes home an awful lot at weekends and I sometimes feel she you know I don't want her to feel she has to, because again I'd love her to what she wants to do at her age you know..... I actually enjoy them doing their own thing. I don't want them being miserable because of me or to stop or not do things because of me”.*

Attempts were made by all participants to maintain their independence and not to be a burden on their families. Becoming a burden to loved ones as their disease progressed was a common fear.

Mary: *“I wouldn't ring *** [husband], as I think he has enough pressure on him and I would talk to him when he's home but no I wouldn't ring him I just know that he would come home and it would upset him too”*

Participants described knowing they had been diagnosed with an incurable cancer and most expressed concerns about dying, and how this would happen. The fear of deteriorating to the extent that they would become a burden to loved ones was expressed.

Mary: *“Yeah, its scary and I would hate to think that I have to go through all these different things, I'd prefer if I'm feeling ok and just leave and forget about it, yeah, and not have to go through different stages and all that..... I just like to think that I wouldn't be left like that and again my independence would be such a huge thing I would just hate if I wasn't able to look after myself or I'd hate to be a burden, they are the things that really really would bother me [tearful]. That is huge for me..”*

Marie: *“Oh I know well I could die with it but I don't know how I'm going to die. Whether it will be quick or slow.....No I don't think much at all about it”*

John: *“No, do you see there is no cure for it but do you see, how long you can hold out is another day's work.....what is the longest that someone ever got?”*

Discussion

Methodological aspects

All the study participants knew the first author in her role as clinical nurse specialist in oncology. This relationship resulted in the participants asking questions about

their care and advice regarding issues related to their treatment or disease, when interviewed. This did pose a challenge, but the first author spent time with the study participants after the interview and discussed issues about their care and treatment that arose during the interview. The difficulty of separating the role of the nurse and researcher in qualitative research is problematic (Dowling, 2006). However, reciprocal knowledge between study participants and researcher can assist the interview process (Murray, 2003).

With hermeneutic phenomenological research, the interpreted themes should be revisited with the participants (van Manen, 1997). Member checking, also known as respondent validation, is widely accepted as a key strategy for establishing credibility in qualitative studies. However, this was not undertaken in view of the participants receiving palliative treatment, and the problems associated with member checking with ill patients (Koch and Harrington, 1998). In the context of research with vulnerable groups, Chouliara et al, (2004) advise that the adoption of a patient-centred approach should guide all ethical and methodological choices. Nevertheless, not adopting member checks has limited the study participants' meaningful participation in the research process (Doyle, 2007).

Aspects of the findings

Participants spoke of loss of jobs, income, friendship, and identity. A cancer diagnosis is nearly always accompanied with loss, ranging from loss of hopes, dreams and physical functioning to loss of life (Robinson et al, 2005). All the participants discussed striving to maintain as normal a life as possible. Each participant talked about the point where their previously 'normal' life ended and their new existence as a cancer patient began. Frequently, participants attempted to

maintain normalcy by balancing family, cancer treatments, other commitments and the effect of symptoms on significant others. The participants' view of relationships as normalising is also reported by Ussher et al, (2006), where some patients found the support group experience challenging and the normalising experience came from family and friends.

For the study participants, meeting others with cancer had a varied meaning. For some it led to reciprocal, supportive relationships. None of the participants attended a support group, although they were aware of the existence of support groups in the area. Two participants described not needing further reminders of their cancer as a reason for not attending. In a recent study (Sherman et al, 2008), examining participation in support groups, it is reported that no lung cancer participated in support groups; however, reasons for this are unclear.

The study participants viewed their bodies with suspicion; symptoms associated with the cancer (such as pain or chest problems) were worried about, and attending the review clinic elicited feelings of anxiety and distress. Due to the incurable nature of their diagnosis, participants were always aware that the cancer would return at some stage, and watched their bodies for signs of recurrence or disease progression. Ovarian cancer patients also can expect a high risk of disease recurrence. Howell et al's (2003) qualitative study, reports that women with ovarian cancer describe waiting for recurrence as frightening, and upcoming hospital appointments are faced with trepidation and fear. Ferrell et al, (2003) also report similar findings among a group of women with ovarian cancer. Moreover, in a recent study reported by Li and

Grigis (2006), 15% of the study group had lung cancer, mostly with advanced disease. The study highlighted that fear of the cancer spreading was one of the greatest worries for the lung cancer group.

All participants reported fatigue as a distressing and debilitating effect of their cancer and treatment, which also negatively affected their perception of self and role in the family. This correlates with findings from other studies examining the experience of lung cancer patients (Cooley et al, 2003; Gift et al, 2003; Fox and Lyon, 2006; Ream et al, 2005; Spathis et al. 2009). It is argued that health care professionals have tended to accept fatigue as an unavoidable side effect of advanced cancer (Ream et al, 2005; Spathis et al, 2009). Furthermore, research exploring the management of fatigue has been limited; usually focusing on correction of reversible causes such as anaemia and encouraging aerobic exercise. However, Temel et al, (2009) found that exercise is not always a feasible option for patients with advanced lung cancer. In their study, 25 patients with advanced lung cancer undertook an exercise programme in hospital, but less than half were able to complete the eight week programme (Temel et al, 2009).

Participants revealed that their hair loss was seen as the outward embodiment of the cancer; a finding reported elsewhere (Trüeb, 2009). Skin rash resulting from treatment with EGFR inhibitors was also a concern for some participants. The rash usually appears on highly visible areas of the body (face, neck, upper torso, and scalp) (Esper et al, 2007). Patients may also experience dry skin, hair changes and nail fissuring. In the unit where the study participants attended, all patients are commenced on a treatment regimen prior to commencing EGFR inhibitors in order

to minimize the rash associated with these therapies, and it has helped to reduce the severity and occurrence of the rash. However, because the rash is associated with a response to the drug (Orditura et al, 2009; Tsimboukis et al, 2009), the physician is usually pleased to see the appearance of the rash, and tells the patient it is a ‘good sign’. A search of the literature reveals a number of studies related to the management of skin rashes (e.g. Tsimboukis et al, 2009). However, no known studies have examined the psychological impact, or the effect of this rash on the patient’s image of self/body image.

Study participants described enduring treatment toxicities but accepted the alternative as even less palatable. Hope is a motivator for the cancer patient to carry on with non-curative treatment (Elliot and Olver, 2007). As long as treatment continues, lung cancer patients maintain hope and cope with the treatment and its side effects (Berterö et al, 2008). Participants also talked about not wanting to spend time in hospital (time wasting); as time was precious in a palliative diagnosis setting, but felt that they had no alternative. A recent study reported by Chu et al, (2007) found that the majority of patients with NSCLC were willing to accept high toxicity from chemotherapy in exchange for prolonged survival, even if the chance of this benefit was small. However, it must be acknowledged that the patients in Chu et al’s study were all chemo naïve, therefore may not have made the same decision once the reality of chemo toxicities was experienced.

Participants spoke about protecting their loved ones; concerns were expressed about causing worry and distress to family members and about becoming a physical burden on loved ones as the disease progressed. The impact of a recurrence of cancer

reverberates throughout the entire family (Vivar et al, 2009). Some participants admitted that, although details of the diagnosis were talked about they did not discuss the future with family members in any detail for fear of upsetting them. This finding is reflected in other studies in the literature looking at the worries of lung cancer patients (Sjölander and Berterö, 2008; Berterö et al, 2008).

All participants also talked about their attempts to maintain independence. Similarly, in a study of patients with a diagnosis of inoperable lung cancer, Berterö et al, (2008) describe maintaining independency and integrity as being the ‘guiding star’ for the participants. Moreover, the importance of maintaining one’s roles and daily routines have been identified as important factors in the quality of life of lung cancer patients (Gallo-Silver and Pollack, 2000; Li and Grigis, 2006).

Finally, all the participants in this study were diagnosed with a terminal illness, and unsurprisingly expressed a fear of what would happen in the future. Anxiety about the future is common among cancer patients (Shaha et al, 2008), and fear of dying becomes more ‘real’ to patients as their disease progresses (Vivar et al, 2009).

Conclusion

The treatment of advanced NSCLC is no longer limited to best supportive care, or even to first line chemotherapy regimens. The development of newer agents, especially targeted therapies have meant that patients with a diagnosis of NSCLC are living longer, and staying on treatment for longer (Vansteenkiste, 2007). Moreover, these newer treatments have different toxicity profiles than the traditional

chemotherapy drugs and these toxicities on patients' quality of life has yet to be adequately explored. Further investigation into the lived experience of patients diagnosed with NSCLC is therefore warranted. Furthermore, despite the improvements in treatment options, advanced NSCLC remains a palliative diagnosis, with a poor long-term prognosis. Therefore, the view that "palliative care is an essential component of cancer care" (Higginson and Costantini, 2008, p. 1422) is particularly relevant to patients with NSCLC.

A resounding finding reported here are the study participants' descriptions of enduring treatment toxicities because the alternative of no treatment was less palatable. The hope that continuing treatment gives to patients with NSCLC therefore emerges strongly, and illustrates the need for 'living well with advanced cancer' as promoted by Higginson and Costantini (2008) who argue that palliative care should be viewed as the interaction between palliative, life extended and curative treatment. Ostgathe et al, (2008) also argue for the early integration of palliative care for patients with NSCLC

The role of ambulatory palliative care services within oncology is gathering momentum (Jordhøy et al, 2001; Strasser et al, 2004). The feasibility of this approach to palliative care for patients with NSCLC is illustrated in a study reported by Temel et al, (2007) where early palliative care for newly diagnosed patients in an ambulatory setting was introduced. However, this approach to palliative care for lung cancer patients requires collaboration between oncology and palliative care practitioners (Harding and Murtagh, 2006). Through early integration of specialised

palliative care, patient care can be improved and unnecessary treatment for patients with lung cancer is limited (Freedman and Zimmermann, 2009).

Key phrases

- Patients diagnosed with NSCLC know that their treatment is not with curative intent and can expect distressing symptoms.
- Patients tolerate the toxicities of their treatment because receiving treatment gives them hope.
- Patients diagnosed with NSCLC strive to maintain normality in their lives and protect their family from their fears.
- Patients with NSCLC express fear of the future and disease progression.
- Patients with NSCLC view their bodies with suspicion and visits to the hospital for review elicit feelings of anxiety and distress.
- Palliative care services in ambulatory care settings play a role in caring for patients with NSCLC.

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Table 1 Study Findings

Theme	Sub-theme
1. 'Maintaining my life' (Lived Space)	a) Striving for normalcy b) Loss c) Facing others with cancer
2. 'The enemy within' (Lived Body)	a) Body as barometer b) Fatigue c) Altered body image
3. 'Staying on the train' (Lived Time)	a) Fear of stopping treatment b) Time spent in hospital
4. 'I'm still me' (Lived Human Relations)	a) Protecting others b) Maintaining independence c) Fear of the future